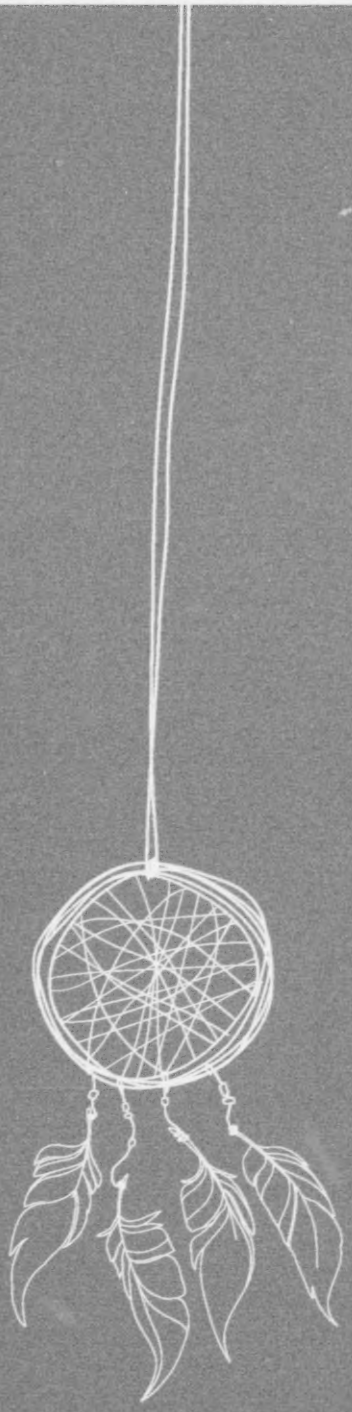

Preventing and Managing Chronic Disease in First Nations Communities:

A GUIDANCE FRAMEWORK

Indigenous Services Canada
Services aux Autochtones Canada

Canada

Également disponible en français sous le titre :
Prévention et gestion des maladies chroniques dans les communautés des Premières Nations : Un cadre d'orientation

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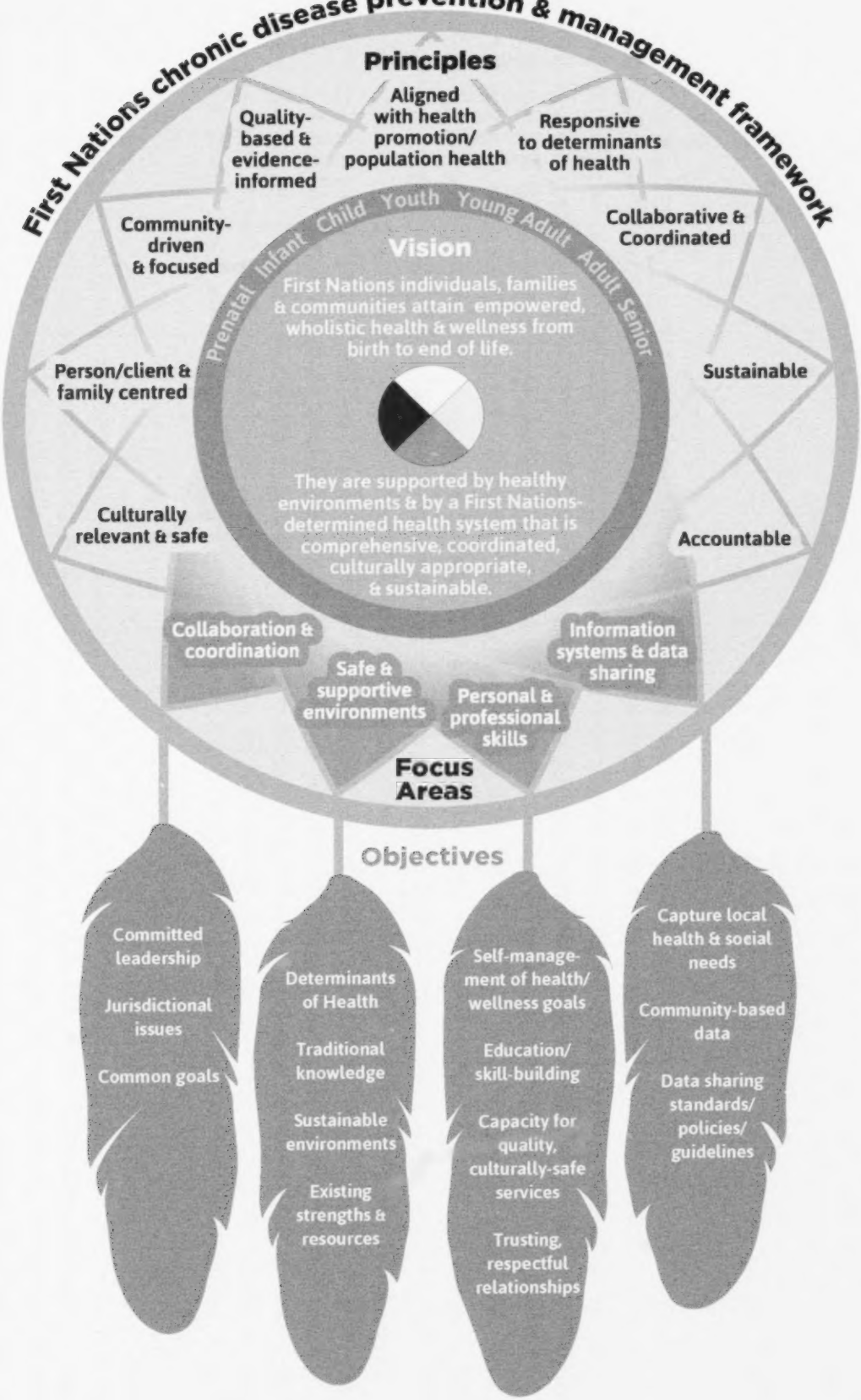
First Nations chronic disease prevention & management framework
Principles
Quality-based & evidence-informed
Aligned with health promotion/ population health
Responsive to determinants of health
Community-driven & focused
Collaborative & Coordinated
Person/client & family centred
Sustainable
Culturally relevant & safe
Accountable
Prenatal Infant Child Youth Young Adult Adult Senior
Vision
First Nations individuals, families & communities attain empowered, wholistic health & wellness from birth to end of life.
They are supported by healthy environments & by a First Nations-determined health system that is comprehensive, coordinated, culturally appropriate, & sustainable.
Collaboration & coordination
Safe & supportive environments
Personal & professional skills
Information systems & data sharing
Focus Areas
Objectives
Committed leadership
Jurisdictional issues
Common goals
Determinants of Health
Traditional knowledge
Sustainable environments
Existing strengths & resources
Self-management of health/ wellness goals
Education/ skill-building
Capacity for quality, culturally-safe services
Trusting, respectful relationships
Capture local health & social needs
Community-based data
Data sharing standards/ policies/ guidelines

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- Provincial and territorial representatives;
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1.0 Introduction

1.1 Background

Historically, First Nations led physically active lifestyles and consumed traditional diets comprised of nutritionally rich foods harvested from the land. Over the past century and a half social, political, economic, and environmental factors forced changes upon traditional lifestyles and practices of First Nations individuals, families and communities. This has led to generally poorer health in comparison to non-Indigenous Canadians[1].

As of 2011, there were 630 First Nations communities in Canada. These communities vary considerably in terms of size, locations and challenges they face. As a whole, First Nations in Canada experience disproportionately higher rates of chronic disease* when compared to the general population. This is attributed to a range of social, geographic and physical factors which are embodied as the social determinants of health[2]. In fact, chronic diseases now constitute the major causes of morbidity, mortality and disability among First Nations. This trend reflects the broader issue of health disparities between First Nations and non-Indigenous populations in Canada.

> First Nations (both status and non-status) make up 2.6% of the total Canadian population

In terms of specific chronic diseases, heart disease is 1.5 times higher among First Nations adults on-reserve compared with the general Canadian population. Type 2 diabetes, once considered rare, is now 3 to 5 times higher. Rates of cancer among First Nations have risen significantly in the past few decades, making cancer among the top four causes of death among First Nations. Incidence of respiratory diseases has increased in First Nations infants, children and youth[3,4,5].

Whether or not people are at risk of chronic disease can be shaped by many factors – some which cannot be changed (family history, genetics, age), but many that can be through healthy lifestyles when there are supportive environments and conditions. This calls for an increased focus on improving the health and wellness of First Nations communities more broadly – not just to treat and manage disease. Rather to prevent chronic disease, and most importantly, to live healthier lives overall. To be successful, these efforts need to respect and leverage the strengths of First Nations, including culture, language, values, and ways of knowing.

Health Services constitute one of the determinants of health. The First Nations and Inuit Health Branch (FNIHB) within Indigenous Services Canada supports a number of community programs and services to prevent and manage chronic disease within First Nations. These include primary care nursing, community health nursing, home and community care, maternal child health, healthy child development, mental wellness, non-insured health benefits, and chronic disease prevention and health promotion. These programs are funded independently, which can be a challenge when trying to link with provincial/territorial systems and to support communication or teamwork between health providers and clients. These challenges reinforce siloed and disease focussed approaches and serve as a barrier to providing client and community focussed services.

In 2013, FNIHB committed to partnering with First Nations to explore ways that better integrate and coordinate programs and services for health promotion, disease prevention and clinical management, with a goal of improving chronic disease outcomes for individuals, families and communities. This commitment built on a

* While often referenced in the singular, the term *chronic disease* represents a *group* of conditions that develop slowly, are of long duration and of generally slow progression. The expressions *chronic disease* and *chronic diseases* are used interchangeably in this document. See **Section 2.1** for further details.

pivotal objective of the 2012 *First Nations and Inuit Health Strategic Plan: A Shared Path to Improved Health*[6], which is to "strengthen access, quality and safety of health services across the continuum of care for individuals, families and communities."

It was with these factors in mind that work on this resource, *Preventing and Managing Chronic Disease in First Nations Communities: A Guidance Framework*, was initiated. This *Framework* provides direction on objectives and actions to improve health outcomes. It identifies opportunities to improve the access of individuals, families, and communities to appropriate, culturally-relevant services and supports, based on their needs, at any point along the wellness to chronic disease health continuum.

1.2 Working towards health and wellness

Within general society, *health* and *wellness* are still often used as synonyms that complement each other. While the two concepts are clearly related, there are important distinctions that inform modern approaches to prevention and management of chronic disease.

Originally, *health* referred to a physical state of being, that is, a physical body being free from illness and disease[7]. From this perspective, health generally involves an end or goal to be achieved – for example, someone who wants to lose weight and lower blood pressure. Once they have done this, they are considered healthy.

Later on, the definition of health was further expanded to include the positive mental status of the individual, where *good health* required being sound in both *body* and *mind*, not just either one.

In contrast, *wellness* is a lifestyle approach that adds the element of *spirit* to that of body and mind, emphasizing the state of the entire being. Rather than a specific end to be achieved, wellness incorporates the attitude a person has towards their health while striving towards a balance of body, mind and spirit throughout one's entire life. A wellness perspective seeks to promote and facilitate both a healthier population and a higher quality of life which is important for people who are trying to prevent or live with a chronic disease.

Initial Western approaches to health have long relied on mitigation of illness and disease and have taken considerable time to evolve towards this concept of wellness. First Nations perspectives on health have been well ahead of the curve. Indeed, First Nations cultures promote a balance among spirit, heart (emotion), mind (mental), and body (physical). As such, this *Framework* was developed with a view to integrate the practices drawn from both Western and First Nations concepts of health and wellness.

1.3 First Nations health, wellness and culture

Throughout the development of this *Framework*, *culture* was consistently identified by First Nations stakeholders as the foundational component of health and wellness. The cultural values, sacred knowledge, language, and practices of First Nations are essential determinants of individual, family, and community health and wellness. These are unique for respective First Nations.

The promotion of wellness, through to the prevention and management of chronic disease, needs to be contextualized to a First Nations environment. First Nations have identified the importance of culturally relevant and culturally safe community-based services and supports (see **Section 1.4**). This approach supports the path to addressing the many determinants of health.

Despite the impacts of colonization, First Nations have maintained their cultural knowledge in their ways of living (with the land and with each other) and in their language. They embrace the

achievement of whole health (physical, mental, emotional, and spiritual) through a comprehensive and coordinated approach that respects, values, and applies First Nations cultural knowledge, methodologies, languages, and ways of knowing.

There is a common view among these communities that culture is vital for healing. It is intimately connected to community wellness. How culture is defined and practiced varies because it is derived from First Nations languages and land(s). Culture is often described as a way of being, knowing, perceiving, behaving, and living in the world. It is recognized as being dynamic because the beliefs, values, customs, and traditions that are passed on between generations continue to be relevant to current realities[8].

Expression of culture, grounded in Indigenous language may take on many different forms. These include, but are not limited to:

- Methods of hunting, fishing and gathering foods;
- Arts and crafts;
- Ways of relating to each other;
- Knowledge that informs family, community, and governance structures;
- The gathering and use of traditional medicines; traditional diets; and
- Spiritual journeying, drumming, dancing, singing, and healing ceremonies.

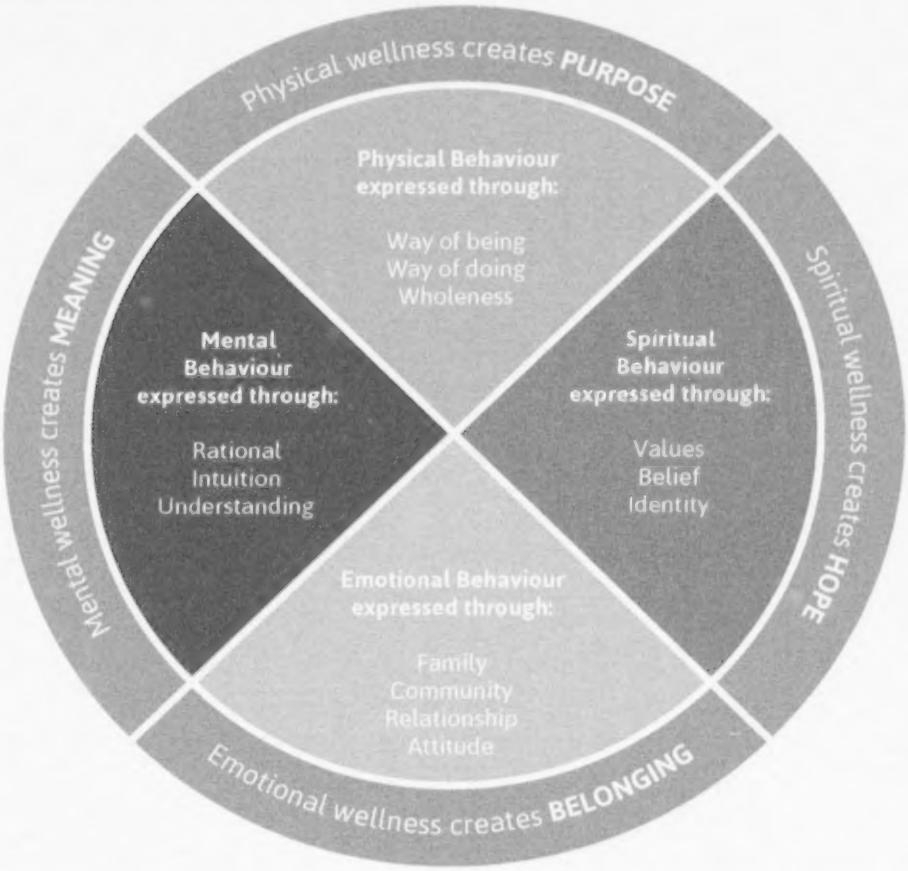
In many communities, forces of colonization and other determinants have displaced First Nations' worldview, culture and their traditional ways of healthy living. These First Nations face major challenges that continue to negatively impact their health and wellness[9]. *The First Nations Mental Wellness Continuum Framework*[10] was completed on a parallel path with this chronic disease prevention and management *Framework*, and shines an important guiding light on a trajectory back to wellness for all First Nations.

1.4 The *Indigenous Wellness Framework*

The *Indigenous Wellness Framework*[11] identifies a whole and healthy person, family and community as attending to their—*physical, mental, emotional,* and *spiritual wellness*. The primary facilitators of this are families, communities, kinship relationships and clan or extended family networks. The key task is to facilitate connections at each of these levels and across the four aspects of self. This *balance* and *interconnectedness* is enriched as individuals have *hope for their future* and those of their families that is grounded in a sense of identity, unique Indigenous values, and having a belief in spirit; a *sense of belonging and connectedness* within their families, to community, with the land and Creation/environment, all of whom are necessary facilitators of an attitude toward living life; and finally a *sense of meaning* and an understanding of how their lives and those of their families and communities are part of creation and a rich history; and *purpose in their daily lives*, whether it is through education, employment, and caregiving activities or through cultural ways of being and doing.

In summary, *hope, belonging, meaning and purpose* are outcomes by which all investments in mental wellness should be measured. These four outcomes have 13 measurable indicators that facilitate these outcomes. The tool that measures hope, belonging, meaning, and purpose is the Native Wellness Assessment™. The results can be used for monitoring individual wellness or aggregated in a community to provide data on community wellness. This is useful for monitoring population health as well as clinical services that include Indigenous knowledge and cultural practices. The Native Wellness Assessment tool can be accessed online at http://nnapf.com/nwa-access/

FIGURE 1: *Indigenous Wellness Framework*, Thunderbird Partnership Foundation



The *Indigenous Wellness Framework* was developed through discussion with cultural practitioners and Elders from across the country and from many different cultures. Although concepts were described in different ways across the various cultures, there were many common threads. Of significance is the common precept that wellness be understood from a *whole person* perspective – the balance of one's spirit, heart/emotions, mind, and physical being.

Spiritual wellness is facilitated through a connection to beliefs, values, and identity. *Emotional wellness* is facilitated through relationships, having an attitude of living life to the fullest, and having connections to family and community. *Mental wellness* is facilitated through an appreciation for both intuitive and rational thought and the understanding that is generated when they are in balance. Finally, *physical wellness* is expressed through a unique native way of being and doing and taking care of one's physical body as the "home" of one's spirit. By attending to these four aspects of being, First Nations peoples have the opportunity to live life as whole and healthy persons[11].

Similarly, the key *wellness outcomes* (**hope**, **belonging**, **meaning**, and **purpose**) are considered to be shared concepts, even if they are described in many different ways across First Nations cultures. Persons who experience wellness have hope, know where they belong in this world, and understand that their life has meaning and that they have a unique and specific purpose in life[11].

Many First Nations communities have reported little success with, and may in fact avoid, services that do not value their way of knowing. As such, other partners in health operating in relationship with First Nations communities have an essential role to play in addressing barriers and challenges in a culturally-appropriate manner. This occurs at various levels of the system. It includes developing culturally-relevant policies, funding mechanisms, and strategies for programs and services, that are managed and implemented by a culturally-competent workforce. Much work remains to be done in order to achieve this goal.

Historically, the strength inherent in First Nations culture was not well-recognized within the medical evidence. However, a growing body of data supports the equal recognition of First Nations knowledge and western scientific evidence. Traditional knowledge, skills, and practices need to be respected by all parts of the health system, and integrated within promotion, prevention and management activities.

The First Nations Mental Wellness Continuum Framework[10] identifies ways to enhance service coordination among various systems and support culturally safe delivery of services to improve mental wellness in First Nations communities. This is a principle shared by the *Chronic Disease Framework* -- both offer a consistent approach to improving programs and services in First Nations communities for better health and wellness outcomes.

1.5 Purpose of *Preventing and Managing Chronic Disease in First Nations Communities: A Guidance Framework*

The *Framework* provides broad direction and identifies opportunities to improve the access of individuals, families, and communities to appropriate, culturally-relevant services and supports based on their needs at any point along the health continuum. It begins with promoting wellness, through to preventing disease, and then on through the various aspects of management and care, including palliative and end of life care.

The *Framework* is not meant to be an implementation plan. Rather, it serves as a non-prescriptive guidance document to help organizations reflect on their own efforts, consider where improvements could be made, and determine next steps that are relevant for their own contexts. The intent is to assist communities in responding to new opportunities as they arise, as well as in reforming and realigning their existing chronic disease programs and services (both prevention and management) according to their own priorities.

Beyond providing this support to communities in shaping their programs, the *Framework* can be used by the Government of Canada to supplement future programming decisions to ensure the best use of any available resources, building on the guidance of First Nations.

It seeks to strengthen integration between and among federal and provincial/territorial chronic disease programs and services for First Nations. For example, the increased use of inter-disciplinary teams that include cultural practitioners can support an integrated approach to service delivery (multi-jurisdictional, multi-sectoral) through a range of service providers.

Regions and communities, working in partnership, will have the opportunity to drive changes to the delivery of community-based chronic disease programs and services. They can develop and implement these changes based on each community's needs and priorities, drawing on the *Framework*. Communities will remain the primary agents determining the structure and composition of their chronic disease programs and services.

That being said, the strategies and activities proposed in the *Framework* cannot be the responsibility of any one party or jurisdiction. Rather, a positive outcome will require that all partners, which can include, but are not limited to – First Nations leadership and communities, Indigenous Services Canada, other federal government departments, as well as provincial/territorial, regional and non-governmental health organizations – collaborate and coordinate their efforts.

Like chronic disease, this *Framework* should not be viewed in isolation, but should be referenced alongside other First Nations-specific resources related to health and wellness. These resources include:

- *The First Nations Mental Wellness Continuum Framework*[10];
- *Honouring Our Strengths: A Renewed Framework to Address Substance Use Issues Among First Nations People in Canada (2011)*[8]; and
- *First Nations and Inuit Health Strategic Plan: A Shared Path to Health (2012)*[6].

In addition, it should be noted that Inuit Tapiriit Kanatami (ITK) has developed *Ilusittiarinniq: Inuit Chronic Disease Prevention and Management Framework* (in press), to address the specific needs of Inuit in Canada.

Some First Nations communities are already acting on at least some of the elements of *Preventing and Managing Chronic Disease in First Nations Communities: A Guidance Framework*. Some of their stories have been captured and are presented as *spotlights* later in this document. These stories are inspiring examples of the strength of communities and the positive outcomes that occur when people come together to work collectively towards a common vision for all community members.

2.0 The Impact of Chronic Disease

2.1 What is chronic disease?

The term *chronic disease* represents a group of conditions that develop slowly, are of long duration and of generally slow progression. Because of this, they are more common later in life, although they can occur at any age. Chronic diseases are sometimes referred to as non-communicable diseases (NCDs), because they are not transmitted from person to person. They generally cannot be prevented by vaccines or cured by medication, although some can be managed. They can share common risk factors[12].

Internationally and in Canada[13], the focus has been on the following more prevalent chronic diseases:

- Cardiovascular diseases (for example heart attacks and stroke);
- Cancers;
- Chronic respiratory diseases (for example chronic obstructive pulmonary disease and asthma); and
- Type 2 diabetes.

Chronic diseases are often silent. As people age, they tend to have more than one chronic disease. For example, in the *First Nations Regional Health Survey* (2012), 62.6% of First Nations adults reported having more than one chronic disease. By age 60, half of First Nations adults were diagnosed with four or more chronic diseases[14].

2.2 Shared risk factors for chronic disease

As listed by the Public Health Agency of Canada[13], the common modifiable risk factors for chronic disease for any population include:

- Smoking (non-traditional tobacco use);
- The harmful use of alcohol;
- Raised blood pressure (or hypertension);
- Physical inactivity;
- Raised cholesterol;
- Overweight/obesity;
- Poor nutrition or an unhealthy diet; and
- Raised blood glucose.

The prevalence in today's society of these major modifiable risk factors, in combination with non-modifiable risk factors such as age and heredity, contribute to the majority of new occurrences of heart disease, stroke, chronic respiratory diseases, and some cancers[12]. The relationship between these risk factors and the most common chronic diseases is similar throughout the world.

Box 1: Social determinants of health[15]

- Income and social status
- Education and literacy
- Social support networks
- Employment/working conditions
- Social environments
- Physical environments
- Personal health practices and coping skills
- Healthy child development
- Biology and genetic endowment
- Health services
- Gender
- Culture

Chronic diseases can significantly affect quality of life and limit daily activities. Those living with a chronic disease require support from family or friends, health care providers and the community wherever they choose to live and/or receive services.

2.3 Social determinants of health

Beyond the general risk factors for chronic disease, many individuals, families and communities encounter additional barriers as they take action towards improving their health and quality of life.

It is well recognized that modifiable risk factors (lifestyle behaviours), such as physical activity and smoking, are influenced not only by individual choice, but also by a variety of social, economic and cultural factors inherent in the environments where people live, learn, work, and play.

These *social determinants of health*[15] (**Box 1**) affect all aspects of health, and provide a more complete understanding of the factors that lead to disparities in the health status of First Nations. A person's ability to live a healthy life depends on these determinants.

Understanding the influence of, and relationships between, the social determinants of health helps to support a more wholistic view of health. It highlights the need for a comprehensive and collaborative approach to improve health that addresses root causes and tries to prevent illness and injury before they occur.

However, successful efforts to improve health outcomes of First Nations need to take into account the broader socio-political environment, economic and historical events that have strongly influenced the current health and social realities of First Nations individuals and communities.

2.4 Indigenous-specific determinants of health

The health of First Nations has been greatly affected by rapid societal changes in the last half century[13]. Many First Nations face critical housing shortages, high rates of unemployment and low levels of educational attainment[16]. By extension, the underlying causes of illness and disease for many Indigenous peoples in Canada are linked to factors such as poverty, substandard housing, barriers to education, and food insecurity.

Rates of food insecurity are much higher than for non-Indigenous households in Canada and are especially pronounced in northern and isolated communities. Food insecurity has been linked to poor dietary quality and intake, multiple chronic conditions (such as type 2 diabetes, heart disease and hypertension), obesity, mental health issues, poor developmental and educational outcomes, and family stress[17 18 19 20].

Box 2: Indigenous-specific determinants of health[21]

- Community Readiness
- Economic Development
- Employment
- Environmental Stewardship
- Gender
- Historical Conditions & Colonialism
- Housing
- Lands & Resources
- Language, Heritage & Strong Cultural Identity
- Legal & Political Equity
- Life Long Learning
- On and off Reserve
- Racism and Discrimination
- Self-determination and Non-dominance
- Social Services and Supports
- Urban and Rural

The *First Nations Wholistic Policy and Planning Model*, first developed by the Assembly of First Nations (AFN) in 2005 and updated in 2013[21], identifies 16 *Indigenous-specific determinants of health* (**Box 2**) that extend beyond issues of health care and service delivery and augment the social determinants of health discussed in **Section 2.2**, above.

Many of these determinants are rooted in a history of colonization and forced assimilation, which has affected First Nations culture, languages, land rights and self-determination. This legacy had devastating effects on First Nations communities and families. It has contributed to lower social and economic status, poorer nutrition, violence, crowded living conditions, and high rates of substance use issues.

As a part of this legacy, several generations of First Nations children were sent to residential schools. As a result, many of the approximately 80,000 former students alive today are coping with disconnection from traditional languages, practices, and cultural teachings. Many suffer from the after-effects of trauma stemming from physical, sexual, and emotional abuse endured as children in residential schools or through the child welfare system. Furthermore, the number of those impacted by past abuses and the disconnection from family, community and culture is far greater than 80,000 as entire families and communities are suffering from the intergenerational effects of the residential schools and child welfare policies. Approximately 66% of First Nations people believe that the relatively poor state of Aboriginal health is linked to the residential school experience and/or the loss of traditional cultures and lands[22].

Taking into account this legacy of colonization, *decolonization* has emerged as a priority for First Nations communities and leadership. Decolonization refers to a process where First Nations people reclaim their traditional culture, redefine themselves as a people, and reassert their distinct identity. It has involved:

- Grieving and healing over the losses suffered through colonization;
- The renewal of cultural practices and improved access to mental wellness resources; and
- First Nations leaders and communities calling for healing, family restoration, and strengthened communities of care[23].

In 2013, the *Assembly of First Nations: First Nations Wholistic Policy and Planning Model*[21] was updated to support the development of a more inclusive, health-continuum approach. The Model puts the community as its core; incorporates four components of well-being (spiritual, physical, emotional and mental); four cycles of the life span; five key dimensions of First Nations self-government; social determinants of health; and three components of social capital (bonding, bridging and linkage).

There have been calls for a parallel process of raising consciousness within Canadian society, aimed at eliminating stigma and discrimination against First Nations people, both on the personal and the structural levels of society. This was reinforced by the recent Calls to Action from the Truth and Reconciliation Commission[24]. Such efforts to provide effective healing programming and to reclaim cultural identity are recognized as keys to revitalizing communities and reducing the impact of chronic diseases.

This *Framework*, while focussing on chronic disease prevention and management, reflects the importance of understanding the complex interactions between all the social and Indigenous-specific determinants of health, and ensuring that action is taken so that all individuals, families and communities have access to the information, supports, care, treatment and management needed for health and wellness.

2.5 Health system challenges

Reports on programs and services funded by FNIHB show that several challenges exist with programs and services provided in First Nations communities[25 26 27 28 29 30 31]. These include:

- Poor coordination and continuity of client care between multiple providers;
- Fragmented client records and inefficient processes for referrals and follow-up;
- The need for better linkages between clinical and community-based programs and services;
- Improved awareness and engagement in health promotion and disease prevention activities; and
- The need for enhanced cultural competency among health staff.

In addition to these findings, the Canadian First Nations Diabetes and Clinical Management Epidemiologic (CIRCLE) study[32], identified the following:

- Gaps in care for diabetes and its complications for First Nations living in Canada;
- A higher rate of risk factors for type 2 diabetes; and
- A higher risk of death from heart disease (a complication of diabetes).

Taken as a whole, these gaps and challenges have contributed to poorer health outcomes within First Nations and point to the need for improved efforts to prevent and manage chronic disease.

By means of a response, developing this *Framework* provided an opportunity to look outside a siloed approach to programming toward a continuum of services and programs that respects a wellness focus. Part of this new approach involves forming new linkages to provide First Nations individuals, families and communities with services when and where they are needed.

Linkages (both formal and informal) that this *Framework* seeks to facilitate include:

- Coordination between chronic disease and mental illness/mental wellness programs;
- Communication and coordination between communities and internal and external service providers;
- Coordination to inform health service delivery, planning, education and quality improvement and evaluation activities; and
- Development of health and social policy.

3.0 Developing a Chronic Disease Prevention and Management Framework with First Nations

3.1 Methodology

This *Framework* was developed using two primary sources: 1) evidence in the chronic disease literature, and 2) Indigenous knowledge gathered through active engagement. The evidence-informed literature provided a conceptual foundation for the exercise. The engagement sessions that followed focused primarily on identifying prevention and management strategies and activities that would contribute to improving chronic disease outcomes.

Various background materials were created based on the literature to guide thinking for the framework exercise and to prepare for and support discussions with First Nations partners and stakeholders. These materials included:

- A concept paper;
- Annotated bibliography;
- Literature synthesis; and
- Regional engagement discussion guide.

3.2 A conceptual approach to preventing and managing chronic disease: the *Expanded Chronic Care Model*

The chronic disease literature suggests that any effective, systemic response across the continuum from health promotion to management of chronic conditions takes into account 1) a population health approach and 2) incorporates activities that support health and well-being. Success requires an integrated, collaborative community-based approach aimed at improving health outcomes.

The *Expanded Chronic Care Model* (ECCM), provided a primary frame of reference to inform the engagement sessions with First Nations partners and stakeholders. The ECCM was developed from the previous Chronic Care Model (CCM)[33], an organizational approach to caring for people with chronic disease in a primary care setting which can be integrated into care across all health care settings.

The CCM recognized that traditional healthcare has had little success in addressing the social, environmental and cultural factors that affect health, and that this had to change. This precursor model was population-based, data driven and creates practical, supportive, evidence-based interactions between a client and a practice team. It identified the essential elements of a system that encourage high-quality chronic disease management by supporting the productive interaction between an informed, activated patient and a prepared, proactive practice team.

However, the functions of health promotion and disease/injury prevention in the community were not explicit in the original CCM. It was more geared to clinically-oriented systems, and was difficult to use for prevention and health promotion practitioners.

The new ECCM model builds upon the original components of the CCM and includes components of the Ottawa Charter for Health Promotion. The Charter recognizes that health is significantly affected by policy decisions in non-healthcare areas, including housing, transportation and food distribution. It called for inter-sectoral collaboration to improve the conditions required for an optimal level of health and well-being. The Charter also emphasizes societal change rather than individual responsibility and supports an active role for communities in setting priorities, making decisions, planning strategies, and implementing them to achieve better health.

The fields of population health and health promotion, brought together by the term *population health promotion*, recognize and work with those broader social determinants of health that can often serve as barriers for both individuals and communities to maintain optimal health.

The ECCM includes elements of the population health promotion field so that broadly-based prevention efforts, recognition of the social determinants, and enhanced community participation, work with health system teams as they manage chronic diseases. The model merges population health promotion with clinical healthcare services and takes a first step in describing how these two approaches can intersect.

In the ECCM, clients are placed at the centre of care. The clients' role in self-care management is supported through:

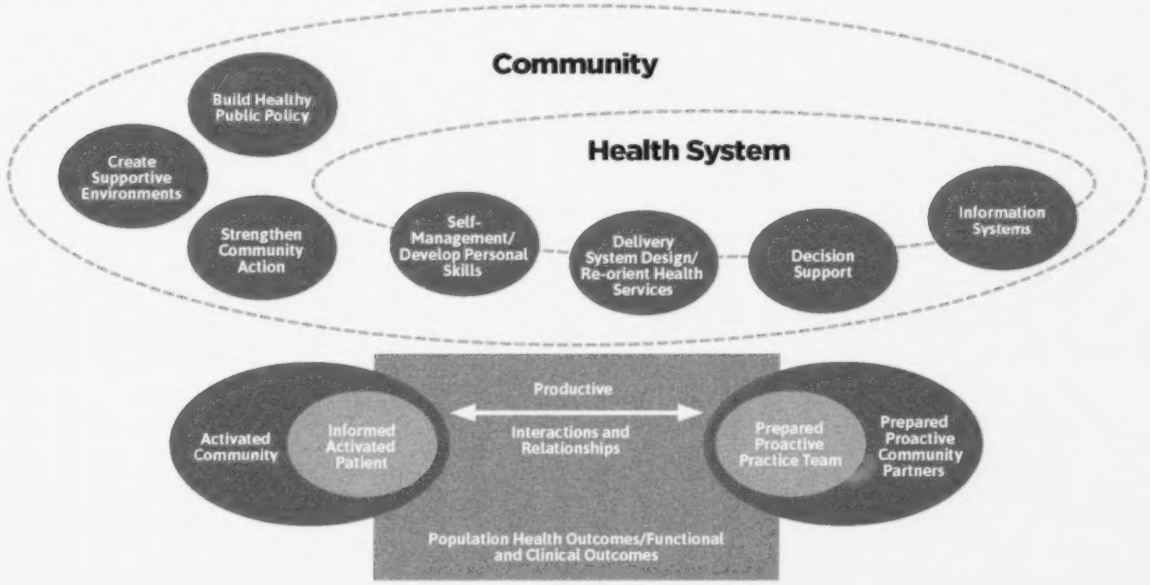
- Skills and knowledge development;
- Linking and integrating programs and services;
- Efficient sharing of information;
- Engaging a broader health team with linkages to community agencies;
- Using a standardized tracking system to monitor clients; and
- Transferring the primary care role to a case manager.

The ECCM components are:

- Support for self-management and personal skills;
- Delivery system design/re-orient health services;
- Decision support;
- Information systems;
- Strengthen community action;
- Create supportive environments; and
- Build healthy public policy.

As demonstrated in **Figure 2**, The ECCM includes a porous border between the formal health system and the community – a graphical representation of the flow of ideas, resources and people between the community and the health system.

Figure 2: The Expanded Chronic Care Model



By incorporating the principles of health promotion and the focus on the determinants of health as directed by a population health approach, the ECCM[33] can be used by the entire practice team in an integrated fashion.

Indeed, the model encourages the creation of broader, interdisciplinary, and inclusive teams that work directly with community supports and leadership. The aim is to support a client in managing their current health concerns by addressing those issues that may be the root cause of their condition, and are presenting barriers to their management. Effective prevention of illness and disability moves beyond the use of clinical services to include the community and relies on inter-sectoral collaboration amongst agencies to create the conditions for this approach.

Such an approach includes developing public policies that promote health, strengthen community action, and create supportive environments. It incorporates community participation in planning, implementation and evaluation of programming and policy development.

In Canada, the ECCM already serves as the basis for Frameworks developed and implemented in the Provinces of British Columbia[34], Alberta[35], Ontario[36], Newfoundland and Labrador[37], and New Brunswick[38].

Internationally, ECCM concepts have informed national strategies in New Zealand, Australia, the United States, the United Kingdom, and other parts of Europe. For example, the U.S. Indian Health Services adapted the initial CCM to create the *Improving Patient Care* model, which supports programs to help reduce health disparities among American Indians and Alaska Native people that are caused by chronic and preventable diseases [39].

The ECCM was adopted as a frame of reference to inform the subsequent engagement sessions with First Nations due to the role of the population health promotion approach and the emphasis on ensuring that community members are involved in planning for new or revised services. This, in turn, served as the basis for this *Framework*.

While not as central to the engagement process as the ECCM, two additional models, the *wellness to chronic disease continuum* [40] and the *life course approach* [41], were sourced from the evidence base and contributed helpful concepts to this *Framework*. More information on these approaches and models can be found in **Appendix 1.**

3.3 Engagement of First Nations across Canada

Supported with a frame of reference provided by the ECCM, engagement sessions were held across Canada from March to October 2013. The purpose was to gather input from First Nations regional and community-based health representatives, FNIHB regional health professionals and provincial/territorial health departments.

Ten sessions were held with a total of 325 participants, which included more than 225 community-based participants. All but one of the sessions was organized by a host First Nations organization. Community participants were chosen by the host First Nations organization as representatives of their community. Following each engagement session, reports were developed based on the outcomes of discussions specific to that region.

Engagement focused on three priorities to develop the First Nations-specific *Framework*: 1) defining a shared *vision*; 2) identifying and describing key *principles*; and 3) exchanging ideas and knowledge on effective *community-based approaches* for promoting health and preventing and managing chronic disease.

Data were collected manually and analyzed by open coding (qualitative coding technique). The resulting summary report of the analyzed data was then reviewed by three external expert reviewers for validation of the method used and interpretation of the data.

Box 3: Engagement at a glance

- 8 Regional engagement sessions held
- 3 Expert reviewers engaged
- 1 First Nations and Inuit National Forum

As a follow-up to the regional engagement sessions, FNIHB hosted a National Chronic Disease Prevention and Management Forum in Ottawa in May 2014. The purpose was to review the combined outcomes of the engagement sessions. The forum discussion and the regional engagement reports served as important resources for the development and initial validation of the *Framework*.

The results of this engagement formed the ***vision***, nine ***guiding principles***, four ***focus areas***, and associated ***objectives*** and ***activities*** (distilled from the input on community approaches) for improved wellness and chronic disease outcomes for First Nations.

4.0 A Guidance Framework

4.1 Vision Statement

For the purposes of the First Nations engagement sessions, ***vision*** was defined as an aspirational statement that communicates both the purpose and value of an approach to chronic disease prevention and management for First Nations communities. It answers the question *"Where do we want to go?"*.

The ***vision statement*** is intended to guide the delivery, design, and coordination of services at all levels of the health system. It recognizes that responsibility for a strengthened system of health care and wellness includes *individual responsibility* for managing one's own health, *communal responsibility* among First Nations people, and a *system-wide responsibility* that rests with individuals, organizations, government departments, and other partners in First Nations health.

The vision for improved chronic disease prevention and management outcomes for First Nations is:

"First Nations individuals, families and communities attain empowered, wholistic health and wellness from birth to end of life. In so doing, they are supported by healthy environments and by a First Nations-determined health system that is comprehensive, coordinated, culturally appropriate, and sustainable."

4.2 Guiding Principles

This *Framework* is grounded in several principles. These principles represent fundamental, shared values that provide direction, set standards, guide efforts and underpin all the chronic disease health decisions that First Nations partners in health make going forward.

To be successful, policies, programs, and services aimed at addressing chronic disease in a First Nations setting need to be:

Culturally relevant and safe

Culture is the underlying foundation of all aspects of this *Framework*. As such, this serves as the leading principle to guide improvement and planning activities at all levels. In order to be successfully implemented, the promotion of wellness, as well as the prevention and management of chronic diseases, needs to be based on the cultural realities of First Nations communities. All partners in health have an essential role to play in addressing barriers and challenges in a culturally-appropriate manner. (See **Section 1.4**.)

Person/client and family centred

Person (or client)-centred care is about what matters to people, putting them and their families at the centre of decisions. It involves considering people's desires, preferences, needs, family situation, social circumstances and lifestyles. It includes respecting people's values when coordinating and integrating care. It's about making sure people have access to the care they need, when and where they need it.

Community-driven and focused

The community is an important aspect of a person's care because it is a source of support and healing. *Community-driven* connects to *Person-centred*, as having a sense of connectedness to ones' community can empower an individual to become more in control of their own health care. This principle refers to the community as both a driver of, and focus of activities. It seeks to align health promotion and chronic disease prevention and management programs and services with the broader priorities and plans of the community.

Quality-based and evidence-informed

This *Framework* was developed with a view to integrate the practices drawn from both Western and traditional First Nations concepts of health and wellness. In a self-determined approach, First Nations communities define and evaluate the data and practices appropriate to their specific circumstances. Fully engaged communities are ones that will ultimately benefit from better health outcomes.

Aligned with health promotion and population health approaches

Health promotion seeks to empower individuals and communities so that all people (including those who are ill and those who are well) are able to achieve greater control over the many factors that affect their health and wellness. *Population health* is an approach aiming to improve the health of an entire group, with an emphasis on reducing health inequities caused by the *social determinants of health* (see **Section 2.3**). Both concepts expand the focus from the individual-level that is characteristic of most mainstream medicine.

Responsive to the impact of Indigenous-specific determinants of health

Indigenous-specific determinants of health include historical and culturally specific factors (such as loss of language, historical conditions, and cultural identity). Ultimately, efforts in health promotion and disease prevention/management can only truly succeed in a First Nations context if they recognize and respond to the Indigenous determinants of health (See **Section 2.4**)

Collaborative and coordinated

Many issues facing communities are dynamic and interrelated. This requires a cooperative, coordinated, and collaborative approach among all partners (including programs, organizations and individuals) who are working to improve health and wellness outcomes with and for First Nations. This approach will help strengthen integration between and among federal and provincial/territorial chronic disease programs and services for First Nations. The *Framework* is intended to encourage and facilitate this ongoing process of respectful engagement, relationship-building, and teamwork.

Sustainable

In order to be effective, health and wellness programs and services for First Nations (including funding) need to be sustainable over the long term. Sustainability requires that First Nations communities have sufficient human resources and infrastructure to support the delivery of these programs and services. Sustainable funding implies making the financial investments necessary to help close the current gap in health status between First Nations and non-Indigenous peoples, accompanied by escalators which take into account population growth, population health needs, and inflation.

Accountable

The direct participation of First Nations communities in the monitoring and evaluation of program results will greatly increase the rate at which the specific needs and priorities of each community are actually being met. Accountability to First Nations individuals, families and communities applies equally to those partners in health who develop, deliver, and implement policies, programs and services.

4.3 Focus Areas

The engagement sessions identified four primary *focus areas* within the continuum of chronic disease prevention and management where improvements could have the greatest positive impact on the health and wellness of First Nations people, families and communities:

- Collaboration and coordination
- Safe and supportive environments
- Personal and professional skills
- Information systems and data sharing

Specific *objectives* for each area were formulated based on collective input from the engagement sessions. These objectives identify and consolidate a discrete set of strategic considerations and suggested activities most relevant to each area. Examples of these *activities* were offered during engagement that could be taken, or were already being taken, to move toward system transformation, and demonstrate how the respective objective might be achieved.

If implemented, the activities would be expected to support an integrated and coordinated approach to health service delivery across the continuum, allowing for flexible programs and services that meet the needs of the First Nations individuals, families and communities, when and where they are needed.

There is inevitable overlap between the four *focus areas*, and none can be acted upon in isolation. Additionally, the *objectives* and suggested *activities* aim to improve overall health outcomes, and to help reduce the disparity between First Nations and non-Indigenous people living in Canada in terms of prevalence of chronic disease and quality of life.

These *focus areas*, *objectives*, and *activities* can be explored by First Nations communities and partners across multiple jurisdictions to plan improvements in chronic disease prevention and management services and to advance this *Framework* if and where appropriate.

1. COLLABORATION AND COORDINATION

Many health agencies – regional/provincial/territorial and federal – are responsible for delivering programs and services along the continuum of health, from promotion and prevention to management and care. Successful delivery requires a firm commitment at the leadership levels of all partners in health to cooperate, coordinate and collaborate among themselves and with other First Nations to define common goals and address jurisdictional issues. This committed leadership – in conjunction with sufficient, needs-based funding of programs and services – is critical to ensuring that First Nations individuals, families and communities receive services when and where they are needed.

OBJECTIVE 1

Leadership at all levels is committed to improving the current health system, creating effective partnerships, encouraging ongoing learning, and maximizing internal and external resources.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
Leadership at all levels fully supports chronic disease prevention and management as a community priority	▸ Develop a community vision for community health and wellness. ▸ Develop a plan for implementing the community vision through various logistics, funding and training. ▸ Adapt budgeting and funding to meet community priorities based on quality, long-term sustainability, and consistency in support. ▸ Make/enhance connections with the provincial/territorial health system in order to collaborate and support seamless chronic disease prevention and management services. ▸ Support local community groups, networks, and activities that focus on health and well-being.
Support the integration of similar community-based programs (e.g., home care services) to improve the delivery of chronic disease prevention and management programs	▸ Establish and maintain relationships with health providers based on an inter-disciplinary approach that promotes team building and care coordination. ▸ House all health care programs/services in the same building in communities to improve teamwork and to give clients easier access to services. ▸ Work with community Elders and/or traditional healers to provide integrative and culturally appropriate care.
Collaborate with other strategies and initiatives relevant to chronic disease	▸ Coordinate with the health promotion and disease prevention/care aspects of existing Frameworks, strategies, initiatives, and programs.

OBJECTIVE 2 Partners in First Nations health identify and address jurisdictional issues so that clients can have seamless access to services that prevent and manage chronic disease.	
STRATEGIES FOR CHANGE	**POTENTIAL/SUGGESTED ACTIVITIES**
Collaborate with other First Nation communities, as well as with regional, provincial/territorial and federal health agencies, to *identify* jurisdictional issues	▸ Create agreements with provinces/territories to clearly outline the kinds of services available to First Nations, and clearly outline federal and provincial/territorial jurisdictional responsibilities for First Nations health service delivery, and accountability for First Nations health outcomes.
Collaborate with other First Nation communities, as well as with regional, provincial/territorial and federal health agencies, to *address* jurisdictional issues	▸ Reduce the impact of barriers on accessing services (such as remoteness, availability of professionals, limited funding, and low access to specialized services like cancer screening and FASD diagnostic clinics). ▸ Establish collaborative practices (a client sees more than one professional at the same visit) in conjunction with the provincial/territorial system, and ensure that cultural supports are available as needed. ▸ Provide timely access to provincial/territorial health and social services, while ensuring that cultural sensitivity, culturally safe and appropriate care, and traditional health and language support are part of this access.

OBJECTIVE 3

Partners and stakeholders in health work together to define common goals and commit to accountability in their efforts to prevent and manage chronic disease.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
Set up fair and effective service partnerships and protocols between the community and the provincial/ territorial service structures, in order to establish inter-disciplinary team approaches with clear roles and responsibilities	▸ Put in place the position of case management/care coordinator to ensure continuity of care and clarity of roles and responsibilities. ▸ Develop integrated care teams and integrated workplans with community-based workers (such as community health nurses, home care nurses, personal and home support workers, including spiritual advisors and traditional healers).
Make adjustments to health care practice using quality improvement methods	▸ Apply clinical practice guidelines, standards, policies and procedures and put in place planned interactions and active follow ups (e.g. care pathways and processes). ▸ Integrate programs (ranging from health promotion, disease prevention, and care management), with a focus on wholistic wellness rather than illness. ▸ Provide local community health centres with the funding necessary to pursue accreditation and enable integration and quality of care.

COMMUNITY SPOTLIGHT:

Opaskwayak Cree Nation Partnerships – Working Together for Health

In order to improve the way health service partners at all levels engage with them, the northern Opaskwayak Cree Nation in Manitoba undertook activities to help outside agencies understand traditional customs and values. The goal was for all health programs and services to be delivered in a respectful, culturally safe way, which would help ensure their acceptability to clients. To achieve this, they:

- Developed a mission statement in Cree, which in English means *working together for health*. Banners with the mission statement and their seven sacred teachings are displayed in all community offices where everyone can see them.
- Built employee performance standards around their mission statement and the seven sacred teachings. Everyone, including the senior leadership team and the members of the Board, are held to the same standards.
- Ensured that 1-2 providers in each practice area speak Cree, since the native language promotes connectedness and a feeling of security for clients.

Clients more readily accepted joint programs and projects being offered, thanks to the respectful ways of working together. Now, the chronic disease prevention and management services delivered by partners have a better chance of success.

2. SAFE AND SUPPORTIVE ENVIRONMENTS

The natural, social and physical environments in which people live, learn, work, and play have a major impact on people's health and quality of life. Inequities in these environments are a root cause of health gaps among First Nations.

Supportive environments are safe and respectful for all who use or inhabit them. They serve a variety of functions. These include:

- Providing access to needed services and promoting healthy and safe physical activities;
- Ensuring access to affordable healthy food and basic necessities;
- Supporting healthy nutrition and lifestyle choices in the workplace and schools; and
- Providing safe places to care for and support seniors, persons with disabilities, and victims of violence.

Supportive environments include the natural world and traditional land in and around communities. Sustaining spiritual links with ancestral lands through traditional languages, knowledge, teachings, practices, and environmental stewardship, are important ways in which First Nations work to create and maintain supportive environments.

OBJECTIVE 1

The social and Indigenous-specific *determinants of health* have been addressed.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
First Nations work with inter-disciplinary and multi-jurisdictional partners on issues related to housing, safe water supply, job opportunities, food security and infrastructure	▸ Create a plan or program, when required or as appropriate, that responds to the housing shortage crisis, environmental hazards to health such as mold, radon, and rodent infestations, as well as needed repairs resulting from the deterioration of housing infrastructure. ▸ Work with retailers, Elders, and other partners to develop/strengthen traditional food access programs (could include community gardening, food preparation, and land-based activities such as harvesting traditional foods through hunting, fishing, and gathering). ▸ Develop and share best practices (as defined by First Nations) that respond to the social and Indigenous-specific determinants of health. ▸ Develop policies that support healthy choices, as well as healthy and safe environments. ▸ Improve collaboration/coordination on these issues between federal government departments.

OBJECTIVE 2

Traditional worldviews, knowledge, and language support positive links to the natural, social, and physical environments.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
Establish practices that protect, preserve, and enhance traditional worldviews, knowledge, and language to support positive links to environments	▸ Develop and implement appropriate curricula and learning resources (in primary, secondary and post-secondary schools) on the historical relationship between First Nations and Canada, colonization and acts of forced assimilation (including the history and legacy of residential schools). ▸ Develop and implement school curriculums which fully respect, protect and preserve traditional teachings and traditional Indigenous languages. ▸ Work with Elders and/or traditional knowledge keepers to provide teachings of traditional knowledge, medicine, healing, languages and cultural practices, both within and outside of school settings. ▸ Host traditional social gatherings (i.e. traditional feasts) and culture camps (to teach traditional languages and traditional ways of living and knowing).

OBJECTIVE 3

Sustainable environments promote healthy lifestyles, and access to healthy choices.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
All partners collaborate to develop public policies that support healthy and sustainable environments	▸ Improve the safety of community infrastructure (sidewalks, playgrounds, fences, buildings, etc.). ▸ Enforce by-laws that promote safe outdoor spaces (e.g. prohibiting dogs from roaming around without a leash). ▸ Modify community infrastructure to support more outdoor physical activity (walking paths, bike parks, better lighting, etc.). ▸ Improve access to living spaces for persons with a disability or chronic disease (residential care or group homes), including support for those with mental health challenges. ▸ Develop an Elders-at-home strategy. ▸ Design and implement campaigns to promote smoke-free homes, workplaces and public spaces. ▸ Designate breastfeeding friendly sites and smoke-free spaces within communities.

OBJECTIVE 4

The community's existing strengths and resources serve as the foundation for progress.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
Encourage all community resources and stakeholders to collectively engage in the self-determination of community health planning	▸ Create a community health committee (representing, among others, day-cares, schools, social services). ▸ Encourage volunteerism by instituting a volunteer recognition program. ▸ Leverage role models and strengthen cultural values through inter-generational sharing and activities. ▸ Implement an awareness campaign on the importance of healthy public policies. ▸ Develop and implement healthy public policies within the community (e.g. training on how to apply animal control by-laws). ▸ Encourage the creation and expansion of youth clubs (such as drumming, singing/dancing groups), in order to develop leadership skills among youth and nurture their self-confidence.

COMMUNITY SPOTLIGHT:

Celebrating Smoke-Free Homes

The community of Sturgeon Lake in Saskatchewan took part in the *Green Light Program*, which celebrates smoke-free First Nation and Metis homes. The program gives people whose homes are smoke-free an energy-efficient green light bulb for outdoor lighting. This signals and celebrates that the home is smoke-free, and encourages other homes in the community to get onboard.

The roots of the program are found in health and wellness surveys conducted in First Nations and Metis communities. Survey results were returned to the communities for reflection and discussion. In all communities surveyed, tobacco misuse (non-traditional use of tobacco by First Nations and Metis) was identified as the most common modifiable risk factor for chronic disease. Communities took the lead, working with health and wellness program staff and researchers on a strategy to reduce tobacco misuse. With funding from provincial and federal sources, they launched the *Green Light Program*.

Principles of the program include local leadership, adapting the program to meet local needs, and building on existing strengths to promote health and wellness. For example, Sturgeon Lake chose to offer smoking cessation and traditional parenting programs. To help build capacity and share information, the *Green Light Program* trains local volunteers as peer counsellors who serve as resources to other communities interested in adopting the program.

3. PERSONAL AND PROFESSIONAL SKILLS

The right kind of resources, learning opportunities, and support (from health providers, family, community members, and/or respected others, such as Elders and peers), are important for self-management. All community members can benefit from chronic disease health/wellness information, self-management resources, and community-based group programs that are accessible and culturally-responsive.

Enhancing professional skills involves equipping health workers with better tools for health promotion, for the prevention and management of chronic disease, and strengthening their ability to support clients in a culturally safe and appropriate manner.

OBJECTIVE 1

Individuals and families develop their own personal health and wellness goals, grounded in traditional knowledge and wholistic health.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
Support individuals and families in their wellness and chronic disease self-management efforts in a culturally safe way	▸ Involve individuals and families, and informal care-givers in shared decision-making, care planning and goal-setting. ▸ Provide clients and their families with access to culturally safe education programs and health information. ▸ Work with Elders to translate western health and wellness, and medication information into a traditional language. ▸ Organize or encourage peer support groups for those experiencing health challenges and/or living with a chronic disease. ▸ Provide individual and family follow-up, using a coordinated inter-disciplinary approach.

OBJECTIVE 2 Appropriate education and skill-building activities are in place to promote health and wellness.	
STRATEGIES FOR CHANGE	**POTENTIAL/SUGGESTED ACTIVITIES**
Encourage use of a community-based approach to health and wellness	▸ Integrate healthy living lessons into the school curriculum, with classes focused on home economics, cooking, health, and physical education. ▸ Provide educational opportunities for youth and children to learn about culturally grounded healthy living and chronic disease self-management practices. ▸ Organize groups for parents to support positive approaches to parenting that are grounded in tradition and culturally-driven. ▸ Identify community champions and role models who demonstrate healthy living practices and inspire others to make healthier choices. ▸ Promote population-specific and culturally-safe healthy living and disease prevention activities through social media, radio, Internet, and community bulletin boards. ▸ Undertake community awareness campaigns to dispel misconceptions about common chronic conditions and diseases.

OBJECTIVE 3 Health providers have the capacity to provide high quality, culturally safe services.	
STRATEGIES FOR CHANGE	**POTENTIAL/SUGGESTED ACTIVITIES**

Equip health providers with the training, skills, competencies, and knowledge necessary to deliver high quality, culturally safe chronic disease prevention and management activities	▸ Provide frontline services with sufficient funding and staffing to:
	  ▸ Ensure health professionals complete mandatory training courses;
	  ▸ Allow for and promote supports for self-care to prevent burnout in the workplace.
	▸ Create a healthy work environment that incorporates leadership, cultural safety, effective teamwork, standardized processes of care, ongoing learning, and measures for improvement.
	▸ Provide regular orientation to health providers on what services/programs and resources are available, and training in how to help clients access needed supports and services ('navigate the system').
	▸ Develop protocols for information and knowledge sharing (i.e. telemedicine) and form linkages to support the facilitation of improved communication, relationship building, and networking among partners.
	▸ Train health workers in cultural safety, communication, motivational interviewing techniques, and chronic disease self-management education techniques.

OBJECTIVE 4 Health providers work with their clients within a relationship based on trust, respect, and open communication.	
STRATEGIES FOR CHANGE	**POTENTIAL/SUGGESTED ACTIVITIES**
Develop the capability of health providers to work with their clients within a relationship based on trust, respect, and open communication	▸ Train health providers in relationship-building, cultural competency and cultural safety. ▸ Train health providers to become coaches, mentors, and facilitators. ▸ Implement cross-training of roles and responsibilities for health providers working in a team to broaden their knowledge and expertise, and to ensure scope of practice is articulated for each health care provider.

COMMUNITY SPOTLIGHT:

Waywayseecappo First Nations: Testing Tuesday

Like many other First Nations communities, Waywayseecappo community in South Western Manitoba reports a high rate of Type 2 diabetes in the adult population and is now seeing a few cases of children with Type 2 diabetes. A successful model of the diabetes clinic/foot care program led this community to launch a new diabetes testing program they developed themselves known as *Testing Tuesday*.

To raise awareness of the program, flyers were delivered by hand to all community members. On Tuesday mornings, individuals come to the health centre after fasting to have their blood sugar level taken, and are then served breakfast. The breakfast provides an opportunity for individuals to discuss their diabetes management with the nurses. On the second and fourth Tuesdays of the month, the centre offers additional screening and blood work. Clients are offered small incentives to attend, such as coupons for local restaurants. The low-cost program has a simple structure, but is appreciated by clients and feedback is positive.

In addition to serving as a diabetes program, *Testing Tuesday* has become a valuable peer support system. Clients learn a lot from speaking with each other about how others manage their condition, and they often come to the program in groups instead of alone. The program is highly locally tailored, culturally safe and client/community-centred. It has helped build community capacity and personal confidence to take control of individual health and wellness. Trusting relationships have been developed through mutual respect and open communication, which make the community stronger in many ways. Care providers learn about the individuals, the community's needs, and new ways to promote health and wellness.

4. INFORMATION SYSTEMS AND DATA SHARING

The use of information systems is key to support processes for change. Information systems capture details on the health and social needs of a community. This data can be used for planning, coordination, decision-making and communicating with health providers. In an ideal situation, information about demographics; health of the community; and cultural, social and economic trends are combined with needs and strengths assessments that are led by community groups.

In order for this to work, information systems used by community-based services (including surveillance reporting and client registries) and those at the provincial/territorial level need to be compatible, efficient, and appropriately integrated. Clear guidelines and data sharing need to be established to ensure that client information is shared in acceptable and safe ways which work towards OCAP® principles.

OCAP® stands for ownership, control, access and possession. It "was created by the First Nations Information Governance Centre (FNIGC) and provides guidance to communities about why, how, and by whom their information is collected, used, or shared. OCAP® reflects First Nation commitments to use and share information in a way that brings benefit to the community, while minimizing harm." (FNIGC, 2014). For more information on OCAP®, go to: http://ir.lib.uwo.ca/iipj/vol5/iss2/3

"Because of the federal Crown's relationship with, and responsibilities to First Nations, Canada collects and holds more information on First Nations people than perhaps any other group in Canada. The collection, use, and disclosure of this information is regulated by the *Privacy Act* (Government of Canada, 1985b), the *Access to Information Act* (Government of Canada, 1985a), and the *Library and Archives of Canada Act* (LACA), all of which apply exclusively to federal government institutions (see Banks & Hébert, 2004). While the *Privacy Act* protects personal information, the *Access to Information Act* and the *Library and Archives of Canada Act* present legislative obstacles to OCAP®..." (http://fnigc.ca/sites/default/files/docs/ocap_path_to_fn_information_governance_en_final.pdf, 2014, p. 2)

OBJECTIVE 1

Community information systems are designed to capture local health and social needs.

STRATEGIES FOR CHANGE	POTENTIAL/SUGGESTED ACTIVITIES
First Nations leaders and First Nation data experts work together so that communities are able to collect, possess and protect their own health data	▸ Develop community Electronic Medical Records (EMR) system and ensure its compatibility with provincial/territorial and hospital systems. ▸ Train community staff and provide ongoing support in using the information system to ensure data quality and skilled analysis. ▸ Ensure the system allows ongoing back up and archiving of information.

OBJECTIVE 2 Community-based data is used to promote quality improvement for First Nations programs and services.	
STRATEGIES FOR CHANGE	**POTENTIAL/SUGGESTED ACTIVITIES**
Develop appropriate community-based health indicators within information systems	▸ Include indicators in information systems that are evidence-based, relevant to communities, and promote quality improvement of programs and services. ▸ Develop a comprehensive and community driven public health surveillance system, including appropriate indicators, as well as systematic and timely collection methods. ▸ Use evidence based indicators to promote quality improvement. ▸ Develop client registries within community information systems.

OBJECTIVE 3 Clear standards, policies, and guidelines on data sharing are in place to ensure client privacy, as well as system safety and security.	
STRATEGIES FOR CHANGE	**POTENTIAL/SUGGESTED ACTIVITIES**
Develop clear standards, policies, guidelines and data sharing protocols	▸ Ensure early, frequent and continuous community engagement in the process to develop standards, policies and guidelines. ▸ Share best practices about system performance, success stories and challenges to help other communities develop their information systems. ▸ Develop a plan on how people (and systems) will work together; clarify roles and access to the system to ensure client health needs and health data remain private, confidential and closely guarded from misuse. ▸ Create data collection systems which would be owned, controlled, managed and housed within communities, and work towards being fully OCAP® compliant. ▸ Formalize standards, policies and guidelines via appropriate agreements between partners.

COMMUNITY SPOTLIGHT:

Ebb and Flow First Nations: FORGE AHEAD

The Ebb and Flow First Nations Health Authority in Manitoba has been working with researchers from Western University on the *FORGE AHEAD* initiative, a type 2 diabetes program that uses data to track results and identify areas for improvement. Designed by and for First Nations; the initiative has two components: primary care and research. With growing numbers of First Nations of all ages developing type 2 diabetes, preventing and managing the condition has become a major focus for this community. The health authority's experience with *FORGE AHEAD* shows how information management systems can help improve care.

When this community joined the initiative, they first attended a training workshop where they learned how to use the data collected through their diabetes program – everything from numbers of participants to lab test results – for quality improvement. They were pleased to learn that much of what they already undertook as a team was considered part of quality improvement...even tasks like taking meeting minutes.

The *FORGE AHEAD* experience has provided the health authority with data to track the increase in diabetes within their community. More people are visiting the clinics, leading to earlier detection. By steadily improving and strengthening their program, they not only observe that more clients are making healthy lifestyle changes – for example, lowering blood sugar and getting more exercise – but they can also measure the change!

5.0 Conclusion

The suggestions provided in this document, by First Nations, are examples of what is required to respond to the increasing rates of chronic disease in order to promote a better quality of life for individuals and families and, ultimately, to improve the health of communities.

Community Spotlights under each *Focus Area* of the *Framework* demonstrate what is currently being done by some communities to achieve better outcomes in the prevention and management of chronic disease. These stories are inspiring examples of communities who have demonstrated strong leadership, effective communication and planning, motivation to improve the status quo, and the importance of recognition and celebration of success.

Partners and stakeholders who took part in engagement sessions wanted the *Framework* to create an *enabling environment* that would guide effective disease prevention and management. The *Framework* development process reflected this request. For the first time, the challenges were addressed according to what communities articulated as their actual needs, using their strengths as a foundation, with a goal of empowering them for the future.

Indeed, one of the pivotal benefits of the *Framework* is that it can be used to support planning at the community level. For instance, it can help to identify joint priorities and opportunities to collaborate with internal and external partners, including provinces/territories and other federal departments. How this *Framework* is implemented by First Nations is at the full discretion of communities, according to each community's needs and priorities and within the limits of the fiscal and human resource realities that exist within Indigenous communities.

The *Framework* can be used at the regional and national levels to strengthen federal chronic disease prevention and management programming and services, as well as to inform policy development.

Some of the work needed to achieve the *Framework's objectives* falls under the mandate of sectors outside the traditional health system, including education, justice, housing, and employment. While the health sector cannot undertake this agenda alone, it can initiate dialogue and act as a collaborator in efforts to improve the well-being of individuals, families and communities. High quality health services need to be supported by policies and programs that allow people time and opportunity to care for each other, without compromising their own health and financial security.

Effective responses in First Nations communities require new and innovative ways of approaching the prevention and management of chronic disease. As such, this *Framework* will prove most effective as a *living* process that looks forward and evolves over time in response to community experiences as they work with the stated *objectives* and suggested *activities*.

The ultimate aspiration is that actions taken now in response to the *Framework* will eventually result in improved health and quality of life, and strengthened economies, for First Nations, as communities make steady progress towards achieving the ***Vision***:

"First Nations individuals, families and communities attain empowered, wholistic health and wellness from birth until end of life. In so doing, they are supported by healthy environments and by a First Nations-determined health system that is comprehensive, coordinated, culturally appropriate, and sustainable."

Appendix 1: Other Models and Approaches

As discussed in **Section 3.2**, the Expanded Chronic Care Model (ECCM) provided a primary frame of reference to inform engagement sessions with First Nations partners and stakeholders. However, two additional lines of evidence contributed to concepts to the *Framework*:

- The Wellness to Chronic Disease Continuum
- The Life Course Approach

The *Wellness to Chronic Disease Continuum*

The *wellness to chronic disease continuum*[40] (see **Figure 3**) sets out the services required within a *whole health system* to prevent and manage chronic disease. It outlines a population health focus; addresses the life continuum, health promotion and prevention at the individual and community level, early detection and screening, management of chronic conditions, and working in partnership; and embeds a client and family centred approach. It describes actions required on an ongoing basis, with involvement from individuals, health providers and the community[40].

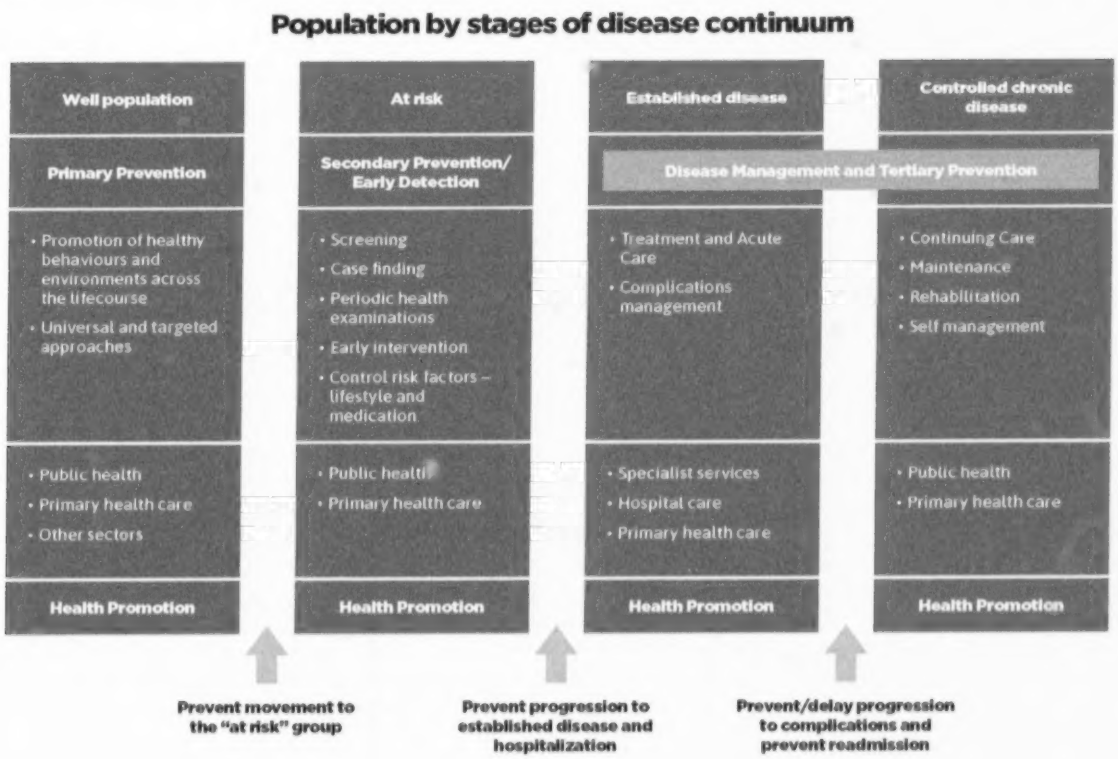
Services available within the health system play a critical role, since they affect health outcomes. This model describes the types of services and how they have different focuses. This means that some services are aimed at the population; others are more public health focused, while others provide individual services. It shows that many types of service are required to prevent and manage chronic diseases[40].

The *Life Course Approach*

The *life course approach*[41] plays an important role in understanding population health and well-being. This model emphasizes how social, biological, psychological and emotional factors contribute to the health of an individual throughout the life span. It is a wholistic model that is compatible with Aboriginal beliefs regarding health and well-being[41].

Key interventions provided in a timely manner can have a significant effect during these critical periods. Each life stage entails unique developmental and physiological requirements, which call for tailored, appropriate interventions to reduce risk factors or to strengthen protective factors. Social conditions and experiences in early life will influence later circumstances and opportunities. In the same way, health-related behaviours adopted early on will influence health in later life[41].

Figure 3: Wellness to Chronic Disease Continuum



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